Opportunities and Action

Transforming Supports in Ontario For People Who Have a Developmental Disability

Ministry of Community and Social Services

May 2006

Ontario

2008-06022/

Message from the Minister of Community and Social Services

I am pleased to present Opportunities and Action – Transforming Supports In Ontario For People Who Have A Developmental Disability.

Ontario is at a crossroads in the evolution of the way it supports people who have a developmental disability. As we prepare to move to a completely community-based approach, we need to make sure that our developmental services system is fair, accessible and sustainable for the future and gives every Ontarian an opportunity to succeed.

Ontario families' lifestyles and expectations have changed over the years. The transformation of our developmental services system needs to not only reflect the changes that have occurred, but to also create a strong foundation of future supports for the next generation of adults with a developmental disability.

Opportunities and Action is an important part of our plan to build a more inclusive province for people who have a developmental disability, and it outlines the Ontario government's response to the challenges facing our developmental services system.

It is also the result of 18 months of research and discussion with a wide range of groups and individuals from across Ontario: people with a developmental disability, their families, service providers, academics and clinical professionals.

All of these people have provided valuable perspectives on what we can do to put our developmental services system in a strong position to address current and future challenges. They have helped us define the principles that we need to follow and signalled the choices we need to make as we focus on coming up with practical, long-term solutions to support Ontarians who have a developmental disability to live as independently as possible and to participate in the life of the community.

I invite you to read Opportunities and Action and provide your comments regarding the transformation of supports for people with a developmental disability in Ontario. This is your opportunity to tell us what you think matters most as we develop a long-term plan to help thousands of individuals with a developmental disability realize their potential and fully participate in their communities.

Thank you in advance for your contribution, and for your ongoing commitment to people with a developmental disability in Ontario.

Madeleine Meilleur
The Honourable Minister of Community and Social Services

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Introduction and Purpose of the Paper

"Our society has changed, families' expectations have changed and we have to change, too. We need a comprehensive plan for the future – one that will lead us for the next 25 years and beyond"

- Honourable Sandra Pupatello, Former Minister of Community and Social Services

The government of Ontario is committed to revitalizing social services and providing effective and coordinated supports for Ontario's children, vulnerable people and families. In the 2004 Ontario Budget, the government announced that the province would be transforming supports for people who have a developmental disability in order to create an accessible, fair and sustainable system of community-based supports.
The province indicated it would work with stakeholders to create a plan that will result in more self-reliant individuals and families supported by coordinated information, planning and supports in their local communities.

"Many families have experienced a shift in their thinking and are ready for transformation."

- Coalition of provincial organizations representing families and individuals with a developmental disability

Many Ontarians share a keen interest in how supports are delivered to people who have a developmental disability. They include individuals who have a developmental disability, their families, agencies that provide developmental services and members of the community at large. Their advice and ideas continue to be a critical part of the transformation of developmental services.
Their feedback will result in a stronger system that helps Ontarians who have a developmental disability to be more fully included in all aspects of society and move toward independent living in the community and that strengthens families' capacity to provide care at home.

Over the past 18 months, government officials and representatives from the Ministry of Community and Social Services met with individuals who have a developmental disability and their families from across the province, as well as with groups representing self-advocates and the agencies that provide developmental services. These individuals, families and organizations provided valuable advice about transforming the way in which supports are provided to people with a developmental disability that helped to develop the strategies presented in this document.

This document serves two purposes. The first is to give everyone who has an interest in the delivery and funding of supports to people with a developmental disability an opportunity to continue to participate in this transformation process by sharing their comments and ideas about the best way to implement the strategy and achieve the goal of an accessible, fair and sustainable approach to the delivery of funding and supports to people with a developmental disability.

The second goal is to introduce the new direction for the delivery of funding and supports based on the advice from stakeholders, in particular individuals and families of people who have a developmental disability.

How to Provide your Comments

The ministry has arranged several methods for people to provide their input and contribute their ideas about this paper.

Please refer to **Appendix 1** for a guide to questions accompanying this paper.

- You may e-mail your comments to:

dstransformation.mcss@css.gov.on.ca

- OR you may mail your comments to:

Developmental Services Transformation Feedback
Developmental Services Branch
Ministry of Community and Social Services
4th Floor, 80 Grosvenor Street
Toronto, Ontario M7A 1E9

- OR you may fax your comments to:

(416) 325-5554 or toll free to 1-866-340-9112

To obtain further information on providing your comments, you may also phone:
(416) 327-4954 or toll-free 1-866-340-8881

Important: Please note that the ministry anticipates a large volume of responses to this discussion paper, and it will not be possible to send an individual letter responding specifically to your comments. We realize that this is a large document. We welcome your comments on all or any of the questions.

Please submit your response by **June 30, 2006.**

The feedback the ministry receives will be carefully reviewed for similar themes and ideas. The information you provide will inform the next step of the process, which is the final policy development leading to the transformation of the sector.

Perspective on Developmental Services in Ontario

Where we have come from

Ontario has provided supports to people who have a developmental disability for more than 100 years. Ontario's early history of developmental services was focused entirely on segregated care in large institutional settings. The first institution for those with a developmental disability was formally opened in Orillia in 1876. By the mid-1970s, Ontario had 19 Schedule 1 (government-operated) institutions. While institutions in Ontario have provided care only to adults since the late 1980s, they were originally residences for both children and adults.

By the late 1960s and early 1970s, the concept of helping people who have a developmental disability to integrate into the general community was gaining worldwide favour. Ontario also began to move in this direction.

In 1974, the new *Developmental Services Act* transferred responsibility for services for people with a developmental disability from the Ministry of Health to the Ministry of Community and Social Services.

By 1975, a limited number of residential and workshop programs had developed and were available in community-based settings. They predominantly consisted of group homes, sheltered employment-related activities and other segregated day activities specifically for individuals with a developmental disability.

Many of the agencies that provide supports and services to individuals and families of people who have a developmental disability today can trace their roots to the community living movement originally started by parents in the mid-1950s to integrate their family members more fully in the community. In the 1970s, people with a developmental disability began to organize to ensure they had a say in how services and supports evolved. This has resulted in a tremendous sense of individual and family ownership in the system.

Some highlights in the history of developmental services in Ontario include:

1977 to 1986 – Two five-year plans were implemented to create community living opportunities for individuals with a developmental disability living in provincially operated institutions. Five of the institutions closed and others downsized. Resources from the closures and downsized institutions were reinvested to enhance community-based services.

1987 – A plan was developed for the future of developmental services, Challenges and Opportunities: Community Living for People with Developmental Handicaps. Challenges and Opportunities committed funds to expand and develop the community service system. An additional five institutions were closed. A commitment was made to phase out large institutions for people who have a developmental disability.

1996 – A four-year community living initiative was announced to help almost 1,000 people move from institutions to live in the community and reinvest the savings in community supports. By 2000, operations had been phased out at three more institutions, and the number of people living in the remaining three institutions was reduced.

2004 – Announcement to transform the developmental services system to better meet the needs of the next generation of adults with a developmental disability. Funding was also announced to strengthen community-based supports, including funding to create new places to live for adults with a developmental disability who will be leaving provincially operated institutions. The government also announced the closure of the three remaining residential institutions for adults with a developmental disability by March 31, 2009.

Over the past three decades, the ministry and its community partners have supported community living for all Ontarians who have a developmental disability. The closure of the remaining three institutions also reflects an international trend and commitment to community living. A successful outcome of the transformation will be the extent to which people who have a developmental disability are recognized and valued as being part of the community.

Appendix 2 provides a summary of milestones in the expansion of community living in Ontario.

Where we are today

Today, Ontario spends $1.35 billion a year on developmental services for children and adults. In addition, approximately $450 million from the Ontario Disability Support Program (ODSP) provides income support for 41,000 adults who have a developmental disability.

Community-based developmental services for adults in Ontario are delivered through a network of approximately 370 board-operated, community-based agencies. These agencies are non-profit corporations that contract with the ministry's regional offices and are funded by the ministry through transfer payments for the express purpose of delivering social services.

Community-based agencies provide a variety of services and supports that are tailored to meet the needs of individuals with a developmental disability and their families to support them to live, work and participate in a wide range of activities within the community.

The ministry's roles in the community-based developmental services system in Ontario are legislator, policy maker, funder and service system manager. Legislation and policy development are established centrally, while funding and service system management take place locally through nine regional offices.

Community-based agencies are accountable to the ministry, through its regional offices, for compliance with the *Developmental Services Act* and its regulation. Compliance is regulated through government directives, service contracts, operational and/or financial reviews, audits, on-site compliance inspections and regular contact with the ministry.

In April 1997, the ministry introduced the Making Services Work for People (MSWFP) initiative. Its goal was to set out a new framework for delivering supports and services for children and for people who have a developmental disability. It also aimed to improve these supports and services by making the most of available resources in each local community and to allocate resources to those most in need.

MSWFP has resulted in single points of access to residential programs in communities across Ontario. To access ministry-funded residential supports, individuals apply to their local single point of access.

A local community planning group is then responsible for reviewing these applications, prioritizing individuals for residential services and identifying the residential spaces as they become available. Community planning groups are typically comprised of community-based agencies and ministry representatives, but groups may include other broader community service providers as appropriate. Every community in Ontario has a community planning group with experience in systems planning and development.

Every community-based agency is expected to participate in the locally established process for accessing supports, in order to coordinate and align available resources. When a residential vacancy becomes available, the community planning group determines who meets the criteria for the vacancy and is most in need of placement.

The services and supports that individuals and their families access through the local developmental services system are based on individual choice, preference and needs to reflect that every person is unique and has individual needs, aspirations and circumstances.

Supports funded by the Ministry of Community and Social Services include:

- Residential services
- Respite
- Community participation supports
- Specialized services for people with specialized needs
- Special Services at Home
- Institutional settings (scheduled to close by March 2009).

Residential supports

Community-based agencies under contract with the ministry currently offer three types of residential services and support to adults with a developmental disability:

- **Group living:** Group homes typically provide 24-hour support for groups of three to six adults with a developmental disability and who need supervision or assistance with activities of daily living.

- **Familyhome arrangements:** The individual resides with a "host family" who receives payment from a community-based agency in return for the support they provide to the individual. Typically, a Familyhome setting supports one or two individuals with a developmental disability.

- **Supported independent living:** The individual typically lives on their own or with another person and receives limited support through the community-based agency. In this setting, individuals receive six to ten hours of personal support per week with activities such as meal preparation, household chores or getting ready to go to work.

Respite
Community-based agencies are also funded by the ministry to provide temporary relief (or respite) for parents or other primary caregivers in meeting their daily responsibilities. Respite is available for short periods of time in the family or caregiver's home, as well as overnight relief outside of the home.

Community participation supports
Community participation supports provide individuals with meaningful daytime activities and increase their independence and ability to participate in community life and/or to develop personal competence to access community supports.

- **Day supports** include such activities as volunteering, life skills and recreation
- **Employment supports** prepare individuals for and/or support people in employment settings that may lead to competitive employment
- **Vocational alternative supports** prepare people for (or support people in) the workplace for no remuneration or for contract remuneration at less than minimum wage (e.g., sheltered workshops) and
- **Adult protective services** provide advocacy and case coordination for people living more independently in the community. These supports are especially important for people who do not have support from their families and assist in keeping vulnerable people safe.

Specialized services for people with specialized needs
Developmental clinical supports provide assessment and treatment to address specific disability-related issues. Supports include:

- Assessment and counseling services
- Speech and language programs and
- Behaviour assessment and/or treatment of behavioural issues.

Health and safety initiatives and funding are provided by the ministry through community-based agencies to enhance the community-based system's ability to provide safe, secure and quality care. Examples include investments in staff training and wages as well as capital funds for purchase of or improvements and repairs to physical supports such as residential buildings, vehicles, lift mechanisms and other supportive equipment.

Special Services at Home
In addition to supports provided by community-based agencies, the ministry directly administers two developmental services programs.

The first is the Special Services at Home (SSAH) program, which was introduced in 1982 to help children who have a developmental disability live at home with their families. In 1990, the SSAH program was expanded to include adults who have a developmental disability, as well as children with a physical disability.

SSAH provides funding directly to families with a child or adult with a developmental disability and/or a child with a physical disability so that families may purchase supports that cannot be provided by a service elsewhere in the community.

Funding may be provided for:

- **Family relief and support** - typically, a special services worker provides respite to the family
- **Personal development and growth** - to help the person learn and develop by achieving specific goals and acquiring new skills.

In recent years, the ministry also introduced several changes to the SSAH program to respond to families' requests for more choice and flexibility in how they receive supports. SSAH funding can now be used by families to purchase a broader range of supports that were not previously eligible for funding through the program (such as day activities, facilitation and planning) and families can get together and pool their SSAH funding to maximize their ability to purchase supports.

The ministry also streamlined the SSAH application process to make it easier for families to apply for SSAH funding. Once a family applies for SSAH and is approved, they will not be required to complete a full application for three years, unless their circumstances change significantly, or they are requesting a different amount of SSAH funding.

In 2005, two additional program improvements were implemented:

- SSAH funding is available to individuals who are not living at home with their families and are not being supported by other ministry-funded residential services.
- Primary caregivers can use their SSAH funding to compensate eligible family members to provide respite or personal development and growth.

Institutional settings

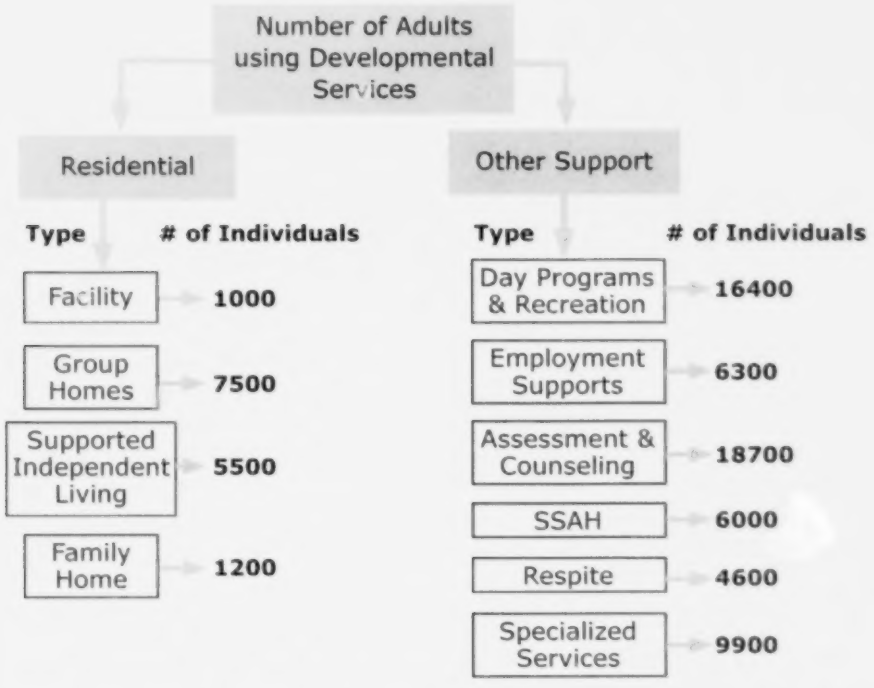
The ministry directly operates three facilities under the *Developmental Services Act, 1974*. These facilities provide a range of residential programs, day programs, specialized supports and leisure activities for approximately 1,000 adults who have a developmental disability. These facilities are scheduled to be closed by March 31, 2009, and the individuals residing in the facilities will move to appropriate community-based settings.

In addition to developmental services funded by the ministry, most adults who have a developmental disability receive income support under the Ontario Disability Support Program (ODSP), and some also use ODSP employment supports leading to competitive employment, e.g., employment preparation and training, technical aids and training in their use and travel and route orientation.

Through this continuum of supports provided within the ministry's existing policy framework, individuals who have a developmental disability and their families are able to access a variety of services and supports that reflect the diversity of preferences, strengths, needs, aspirations and circumstances of individuals who live in the community.

Appendix 3 provides a summary of expenditures in developmental services.

The following illustration shows the number of adults receiving specific developmental services. Developmental services (e.g., SSAH and respite supports) are also provided to children who have a developmental disability.



People may also receive ODSP support ranging from $8,700 – $11,500/yr depending on the type of residential supports/shelter costs

Figures have been rounded and are a three year average of 2001/02; 2002/03; 2003/04 service data

Changes in developmental services in recent years have been influenced by a focus on citizenship. Today it is recognized that people who have a developmental disability want to, and can, participate in their community. The idea of citizenship and enabling people to have control over what they do with their lives was central to an agreement struck by the Federal/Provincial/ Territorial Social Services Ministers in 1998. The agreement, titled In Unison: A Canadian Approach to Disability Issues, outlined a vision of full citizenship and full participation for people with disabilities in all aspects of the community.

The *Accessibility for Ontarians with Disabilities Act, 2005* was enacted in order to achieve accessibility for Ontarians with disabilities. This will be accomplished by developing, implementing and enforcing accessibility standards concerning goods, services, accommodation, facilities, buildings and employment. Standards will set out the measures, policies, practices and other steps needed to remove and prevent barriers in these areas for people who have a disability.

The transformation of developmental services in Ontario includes the development of a long-term plan that focuses on a citizenship agenda that advances the idea of full participation of Ontarians with disabilities in all areas of society. Living in the community is not enough. True transformation will have occurred when people with a developmental disability are part of the community.

Stakeholder input and discussion

Individuals, families and service providers have always played a central role in shaping developmental services in Ontario. The government wants to provide opportunities to hear their views as we work together to transform the sector.

One step in the development of a plan to transform developmental services was the formation of a Joint Ministry/Developmental Services Partnership Table, which has representatives from self-advocates, family and service provider associations, the Ministry of Community and Social Services and the Ministry of Children and Youth Services.

In October 2004, the Partnership Table prepared a Preliminary Discussion Paper: Transforming Services in Ontario for People who have a Developmental Disability. The ideas in the document were presented for the purpose of discussion, and Partnership Table members used the paper to obtain feedback from their members in the fall of 2004. Organizations held discussion sessions with their members, and some posted the paper on their website. As well, individuals and groups who asked the ministry about the work of the Partnership Table were provided with a copy of the paper and given the opportunity to provide feedback to the ministry. Over 100 responses were received from individuals and families, agencies, family networks and provincial organizations representing thousands of people. Most of the quotes that appear in this paper are extracted from the responses to the discussion paper.

Other activities that provided input into the transformation strategy were:

- Local meetings throughout the province held by the Minister's Parliamentary Assistant (Disabilities) with individuals and families. The Parliamentary Assistant spoke with over 180 people, most of whom were not affiliated with one of the Partnership Table member organizations or a local service provider.
- Six Policy Forums that were attended by approximately 1,000 experts in the field who provided the ministry with advice and ideas.
- Detailed research conducted by ministry staff of developmental services approaches in other jurisdictions.

Several themes emerged from the responses to the Partnership Table paper, local meetings with the Parliamentary Assistant (Disabilities) and the policy forums that indicated changes are needed in developmental services to:

- Strengthen and support individuals and families
- Create a fair approach to supporting individuals and families
- Provide people with more choice and flexibility
- Create a sustainable service system that provides quality supports and
- Improve specialized services for people with specialized needs.

This paper is intended to stimulate a broad public consultation on the long-term plan and give all individuals, families and stakeholders an opportunity to make their views known about how the transformation strategy can be implemented.

Opportunities and Action – Objectives and Strategies of the Transformed System

There are several features aimed at transforming the system of supports for adults with a developmental disability into one that exemplifies community engagement and is fair, accessible and sustainable:

- Fairness is achieved when processes allow people with similar situations to receive similar supports across the province.
- Funding and supports will be more flexible and individually tailored. People who have a developmental disability will have opportunities for self-determination and to participate in decision-making about the funding or supports they receive with the help of a planner/facilitator, where necessary, to participate.
- Access to supports will be through a more streamlined and clearly identified gateway that will provide people who have a developmental disability and their families with comprehensive information about available supports. A consistent approach will be in place to help people access the appropriate supports according to their individual plans of support and, wherever possible and desired, integrate with services generally available to members of the community.
- In the long term, the developmental services system will be more sustainable through the ministry's plan to improve access to specialized services, gather better data to strengthen planning capacity and improve accountability for funding.

The long-range outcomes of a sustainable sector will be supporting people to live in the community characterized by:

- Enhanced capacity, both in the larger community and through agencies, to provide a broad range of supports to people based on their individual needs
- More choice and flexibility for individuals and families through direct funding and portability of supports
- Access to a broader range of community supports, including specialized services
- Better management of funding pressures
- Helping facility residents to live in the community and
- Clearer roles of individuals, families, agencies and government.

The ministry's strategy to transform the developmental services sector is focused on the strategic areas people identified over the past 18 months and is presented in this paper in two broad sections.

Section 1 seeks input on the most effective ways to implement supports for individuals and families in the areas of:

- Supports for inclusion and community engagement
- Improved respite supports for caregivers
- Partnerships with families on residential supports
- Supports for young adults when they leave school
- Older adults accessing supports for seniors
- Specialized services to support people with specialized needs
- Effective use of the tax system and wills and trusts to help families plan for the future care of their family member
- Quality supports and services.

Section 2 provides information about the ministry's plan for systems transformation in the areas of:

- Independent planning
- Eligibility for services and supports
- Application for funding supports
- Accessing supports
- Funding approaches.

Vision and Principles to Guide Transformation

Transformation of the delivery of supports to people who have a developmental disability is based on the over-arching principle that people who have a developmental disability are people first, and focuses on independence, dignity and self-reliance for people with a developmental disability. The fundamental vision is to support people to live as independently as possible in the community and to support the full inclusion of Ontarians with disabilities in all aspects of society.

In the fall of 2005, the ministry released the document Thriving Communities: A Strategic Direction for the Ministry of Community and Social Services. Thriving Communities is a framework that outlines the ministry's vision and mission, the principles it will uphold, the priorities and strategies that will guide the ministry and its future directions.

The future course of developmental services in Ontario is based on six underlying principles that are inspired by this strategic framework:

- Citizenship
- Fairness and equity
- Accessibility and portability
- Safety and security
- Accountability and
- Sustainability.

i) Citizenship

Supports for people who have a developmental disability will:

- Contribute to the development of thriving communities sustained by the economic and civic contributions of Ontarians who have a developmental disability
- Enhance the community perception of people who have a developmental disability and promote participation of people who have a developmental disability in the community
- Wherever possible and desirable, integrate with services and supports generally available to members of the community
- Promote self-determination by providing direct funding and creating opportunities for families to invest their own resources to help their family member in the future
- Respect the uniqueness and diversity of individuals
- Recognize that people who have a developmental disability have the same right as other members of society to participate in community life and to realize their individual potential for physical, social, emotional, intellectual and spiritual development
- Respect individuals' right to receive supports in French as set out in the *French Language Services Act*.

"There is a general feeling that people with disabilities are not seen as fellow citizens. People feel their rights are not recognized in the same way other peoples' are."

- Self-advocate organization

ii) Fairness and equity

Supports for people who have a developmental disability will:

- Focus on increased independence, employment, voluntary and recreational opportunities and integration into the community
- Be equitable so that people with similar situations receive similar supports across the province
- Create opportunities in everyday life that are the same, or as close as possible, to norms and patterns that are valued in the general community
- Be tailored to meet their individual needs and goals
- Be appropriate to their age, support needs and cultural affiliation.

iii) Accessibility and portability

People who have a developmental disability will have:

- Funding and supports that are flexible and individually tailored
- Portable funding that allows supports to continue if they move to another community within the province
- Opportunities to participate in decision-making about the funding or supports they receive and the help of an independent planner, where desired, to participate.

iv) Safety and Security

Supports for people who have a developmental disability will:

- Have appropriate supervision and staffing
- Have regard for the benefits of activities that prevent the occurrence or worsening of disabilities
- Be designed and administered in ways that respect the rights of people who have a developmental disability to privacy and confidentiality
- Promote safety, especially for those who may be at risk.

v) Accountability

Service delivery for people who have a developmental disability will:

- Be accountable to people who use their supports, and to the ministry for providing information to assess the quality and outcomes of their supports
- Be characterized by meaningful engagement with the public and those affected by proposed changes and provide ways for people who use the supports to participate in the planning and delivery of the supports they receive.

vi) Sustainability

The delivery of funding and supports to people who have a developmental disability will feature:

- A long-range plan for the next ten years and beyond
- A mechanism that allocates funding based on individuals' assessed needs and within available resources
- Better management of funding pressures through strengthened planning/forecasting and matching of funding to needs so that pressures will be minimized
- Better data to strengthen planning capacity and accountability for funding and to use as a basis for funding decisions
- Clearer roles of individuals, families, agencies and government.

Transformation of the delivery of funding and supports to people who have a developmental disability is crucial to continuing to provide effective supports to people so that they are able to live as independently as possible in the community. Another critical step is the need for a commitment from all segments of society to help people who have a developmental disability to realize the goal of being fully included in society and to have the same opportunities as other Ontarians to participate in the life of the community.

Transformation recognizes that people have the right to choose the community that best serves their needs. Some people find community when integrated into the mainstream. Others define their community through the support they receive from agencies. For others still, community and their immediate family are synonymous. An outcome of the transformation will be to recognize and honour peoples' choices.

Section 1: Supports to Individuals and Families

Most people who have a developmental disability live in the community in a variety of settings: with parents or other relatives, in group homes or in their own homes or apartment, with varying degrees of support. Sometimes, however, physically living in the community does not mean a person is fully included in that community. Attitudes in society need to shift to value the contributions of people with a developmental disability.

Many people who have a developmental disability are living quite independently in their own home in the community. Some have paid employment, are married and have children of their own. People in these situations may need to access a different range of ministry-funded supports than people who live at home with their family. For example, people living more independently may receive support from an adult protective services worker. While most people with a developmental disability have caring and supportive families, others do not. Supports need to be available for people who do not have family or agency support.

For people with a developmental disability who live with parents or other relatives, families are the most important providers of care. This includes not only parents, but also brothers and sisters who often play an increasingly important role as their parents age. These individuals may need ministry-funded day activities as well as some type of specialized services, and their families might require respite supports.

Families have demonstrated extraordinary commitment to caring for their family members in their own homes, as well as creating opportunities for participation in society and encouraging independence. However, the changing patterns of family life have had an impact on the capacity of families to address all the challenges of their caregiving role, and families often need help.

Government needs to support individuals and families in their efforts to support their family member at home and to help people achieve their goal to participate fully as citizens in the life of the community.

We would like to hear your advice on how to implement the following strategies that are proposed to improve supports to individuals and families.

1.1 Support for Inclusion and Community Engagement

While a wider spectrum of community residential options will focus on developing choices for people of how and where to live in their communities, government will also look at other ways to foster independence, productivity, belonging and participation in communities.

For example, the Passport Mentoring initiative was introduced in 2006 to establish one-on-one relationships between adult mentors who have a developmental disability and students who have a developmental disability. The initiative is intended to provide students with exposure to post-secondary experiences and options, which will enhance their opportunity to make informed decisions and to connect with these options.

A partnership is also needed among individuals, families, agencies and government to support efforts that create a positive public awareness of people with disabilities, strengthen their voices and enable them to participate and belong in their communities.

In addition to breaking down societal barriers, it is essential that appropriate cultural supports be available and that communities be encouraged to develop supports to meet the needs of people in their communities who have a developmental disability. Sometimes, supports need to be gender specific.

The *Accessibility for Ontarians with Disabilities Act, 2005* is an important tool that promotes the development of measures, policies, practices and other steps to remove and prevent barriers for people with disabilities from participating in society.

To complement the supports provided by the developmental services system, environments need to be created in which people with a developmental disability are valued and recognized for their strengths and abilities. Such environments must exist in all parts of society to prevent barriers in the areas of goods, services, accommodation, buildings and employment for Ontarians who have a disability.

1.2 Respite for Caregivers

Among the range of supports provided in the developmental services sector, respite (often referred to as parent relief) can have the most profound impact on families' capacity to provide the care their family member with a developmental disability needs. Many families report that having occasional, brief breaks from their caregiving responsibilities can make an immeasurable difference in continuing to care for their family member at home.

The current system of respite supports needs to be better coordinated and less fragmented in order to improve the benefits these supports can have for families. The Ministry of Community and Social Services and the Ministry of Children and Youth Services currently fund five separate respite supports for families who are caring for a person with special needs at home:

- Enhanced Respite for Medically Fragile and/or Technology Dependent Children (children only)
- Assistance for Children with Severe Disabilities (ACSD) (children only)
- Out-of-Home Respite Supports (children and adults)
- In-Home Respite Supports (children and adults)
- Special Services at Home (children and adults).

The Enhanced Respite, Out-of-Home and In-Home Respite programs exclusively fund respite supports, whereas respite is a component of a broader range of services and supports available through the SSAH and ACSD programs.

Potentially, families caring for a family member who has a disability may access funds from each of the five service streams, provided they meet established eligibility criteria. However, each program has different policies, procedures, eligibility criteria, funding limits and service parameters.

The differences in policies and program design make it difficult for families to understand what supports are available and how to access the supports they need.

Administratively, the funding and delivery of respite supports are complex, with programs operating under one or more of the following legislative authorities:

- *Ontario Disability Support Program Act, 1997*
- *Child and Family Services Act*
- *Developmental Services Act.*

In 2005/06, the ministry, in partnership with the Ministry of Children and Youth Services, conducted a comprehensive review of all respite programs in both children's and adult developmental services in order to develop a plan for the redesign of these supports to improve integration, streamlining and coordination of the supports, as well as increasing fairness and accessibility to families.

1.3 Partnerships with Families on Residential Supports

Based on their individualized plan, some people may want some form of residential service outside the family home.

As described earlier in this paper, the ministry currently funds transfer payment agencies to operate three main community-based models of accommodation that provide different support levels depending on people's needs:

- Group Living Supports
- Supported Independent Living Program (also known as Independent Community Living)
- Familyhome Program (similar to foster care, not with their family of origin).

Families have an important role to play in securing a suitable place for their family member to live. Some families may prefer to explore using their own resources to provide the accommodation rather than using the traditional services such as group home, Familyhome program or supported independent living programs offered by the formal service system.

The ministry is developing a strategy to help families use their own resources through a Home Partnership Strategy that could combine individuals' wishes for flexible, person-centred residential options with government-funded services and supports.

The ministry will review existing policies and rules that define how individuals who have a developmental disability and their families may use provincial government funding and identify how to ease restrictions on the use of funding allocations.

In keeping with this direction, the ministry recently introduced a change to the Special Services at Home (SSAH) program to allow individuals to continue receiving SSAH funding when they are not living at home with their families and not residing in ministry-funded residential accommodation. In addition to the support SSAH provides in helping people when they live with their families, the new policy updates the SSAH program and creates a better fit with the contemporary reality of more people with a developmental disability moving from the family home to living independently in the community.

There are other creative residential options to provide the kind of individually tailored living arrangements that many people are seeking. One example is a co-op housing arrangement that is jointly owned by families with supports purchased and/or provided by family, friends and community members. Each individual supported in the co-op has a detailed support plan that outlines the supports they need in the home.

A residential alternative that was developed in Saskatchewan is an independent living arrangement where the family employs a caregiver who lives with their family member as a roommate. Two people – typically university students – are hired as live-in helpers to provide care and support. In this situation, the family submits a proposal seeking funding from the province, and the agency in turn flows the funding to the family.

These examples are just some of the ways that partnerships between the ministry and families could result in a more individualized approach to community living for people with a developmental disability.

The ministry will also work with other ministries and levels of government to identify and address any tax issues (capital gains, etc.) related to owning a second home purchased for a family member who has a developmental disability.

Families will also be helped to explore various home ownership possibilities and provide information on how they could investigate the following options:

- Placing the family home in a discretionary trust
- Selling or leasing the family home to a service provider or housing association
- Gifting the family home to a service provider/ organization with conditions for its use
- Building or buying a property for their son or daughter to rent from their parents
- Buying a house/condo with other parents, sharing ownership and pooling support services.

Overall, the residential strategy is intended to create a broader range of residential opportunities for more people and support families in their efforts to help their adult children move into their own home and live more independently in the community.

1.4 Transition across Life Stages

Despite the wide range of supports offered in the developmental services sector, one of the keys to creating a sustainable service system is to engage in early planning with individuals and families through times of transition to make successful adjustments across life stages. Many people have identified the importance of advance planning and helping individuals and their families to anticipate and envision these transitions and their implications. Proper planning is needed for people, beginning at age 14, to help create a smooth and effective transition for people once they turn 18 years old and move into the adult developmental services system.

Proper service planning is also crucial for maximizing opportunities for older people to access seniors-related services, including those of the Ministry of Health and Long-Term Care.

a) Youth transitioning from school

Moving into adulthood is both an exciting and a stressful life transition. There are decisions to be made regarding future directions and life choices. There is the move to greater independence from parents, with increased responsibilities on the part of the young person and reduced obligations on the part of their parents.

For young people who have a developmental disability and their families, the transition from school to adult life presents additional challenges. As students, most young people with a developmental disability attended schools in their community. The school setting provided not only an educational program, but also opportunities for socialization and structured activities for most of the day. Once they leave the school setting, they have fewer opportunities for employment,

post-secondary education and living outside of the family home than peers without a developmental disability. In addition, opportunities for socialization and activities outside the home are no longer so readily available.

Because children who have a developmental disability are more dependent on parental support, the move to greater independence as they reach adulthood can be more difficult for both the young people and their parents. In fact, parental responsibilities often increase when the school system no longer provides daily activities for young people with a developmental disability (the maximum age for students in the school system is 21 years).

For some time, day supports funded by the Ministry of Community and Social Services have been critical to supporting adults who have a developmental disability living in the community. Young people today are the first generation of students that have gone through an integrated school system. Supports need to be in place to provide meaningful community-based activities for this generation of young adults.

"[My daughter] has grown up in a society that stimulated her, maximized her capabilities and encouraged her to believe that she can be an active member of the community. When she completed school, all of those support systems disappeared with nothing to take their place."

- Parent

To assist these young people and their families, the ministry introduced Foundations: A Transitional Initiative for Young Adults with Developmental Disabilities. Since the introduction of the Foundations program in May 2000, a total of $17.5 million has been invested to fund about 100 programs serving over 2,200 individuals.

In July 2005, the Minister of Community and Social Services announced funding for a new initiative called Passport that is designed to enhance day supports for individuals who have a developmental disability who have left school and are seeking meaningful community participation supports. The former Foundations programs are now a part of the new Passport initiative. Passport consists of the following key components:

- **Mentoring:** An in-school opportunity will expose students who have a developmental disability at the secondary level to post-school experiences and options.
- **Planning**: Individuals and families working in partnership with educators and local agencies designated by the Ministry of Community and Social Services' regional offices will develop individual transition plans as identified under regulation of the *Education Act*. Some funding will also be available through Passport to assist with planning for individuals who are no longer in school.
- **Funding of community participation supports:** Individuals and/or families will have the option of direct funding or agency-based programs for community participation supports.

In combination, these activities will improve the quality of participation in the community by providing adults who have a developmental disability with meaningful supports that focus on individual goals, work activities and community participation activities.

In addition, the ministry needs to forge stronger cross-sector linkages at all levels of the system (students, their families, ministries, school boards and community agencies) to promote better systems planning and coordination and smooth transition from school to life in the community.

"Develop a clear, standardized transition process for each person with a developmental disability (for example school to day program, school to higher education) beginning several years before graduation."

- Agency

The ministry will work together with the Ministry of Education, the Ministry of Children and Youth Services and the Ministry of Health and Long-Term Care to develop policies and strategies to better support and guide transition planning as mandated by the *Education Act*. This could include:

- Ongoing information sharing to identify linkages and issues that need to be addressed
- Identification of planning expectations, roles, responsibilities and accountabilities at all levels of the system as they apply to transition planning
- Development of a joint education/community transition planning, model/protocol that would describe a process for joint involvement in transition planning including appropriate two-way communication between the education and community service sectors at the local level and
- Comprehensive and ongoing training for school board and community agency staff to provide effective implementation and maintenance of the transition planning model/protocol.

A range of supports will continue to be offered to meet individual needs, including leisure and recreation activities, physical activity and non-competitive employment.

There will also be a range of service delivery approaches, depending on individual needs. For some people, this may involve getting help to access community-based supports and services. For others, it could be agency-based programs where young people participate with a group of people who have similar needs. Still others may choose an individually tailored solution to their activity needs.

People who have a developmental disability wishing to pursue competitive employment may also receive support from the ministry's Ontario Disability Support Program Employment Assistance supports.

b) Older adults accessing supports for seniors

In the same way that there are challenges for young people becoming adults, becoming a senior is also challenging.

In the past, the life expectancy of people who have a developmental disability was shorter than for the general population. Today, with improvements in quality of life, more community resources and advances in medical knowledge, people who have a developmental disability can look forward to older adulthood. However, recent research has also reported accelerated aging among individuals with a developmental disability, including earlier onset and higher risk of dementia-related diseases. Other health problems such as diabetes, heart disease and cancer are also reported by service providers. As individuals age, they need higher levels of care.

Families play a very significant role in supporting the vast majority of people who have a developmental disability. In families where the person who has a developmental disability is approaching older adulthood, family caregivers are already in their senior years. As they age, families are no longer able to provide the same level of support for their sons and daughters. One or both parents may require support themselves. A dilemma for parental caregivers is that they must deal with their own aging along with the aging of their sons or daughters who have a developmental disability. The need for people who have a developmental disability to access supports for seniors is expected to increase.

Older adults who have a developmental disability should be included in the life and supports of the community just like anyone else. Some already access supports for seniors such as recreational activities and some receive support such as home care. However, access varies across the province.

There is currently limited and inconsistent access to the continuum of community supports for seniors who have a developmental disability (i.e. recreation, information services, meals on wheels, home visiting, adult day activities and residential supports).

"The supports associated with aging span social services, medical services, mental health services and long-term care. The need to integrate policy, funding and service delivery across these sectors and respective ministries is paramount in addressing this growing challenge."

- Organization representing agencies

Most developmental service providers need more experience in supporting older adults who have a developmental disability, while some are uncertain about whether long-term care supports can provide the appropriate care. Health and developmental services operate in different service systems, and there are under-developed linkages between ministries.

It is important that there is a shared leadership approach between government and community partners to identifying issues, planning, service delivery and accountability for both developmental services and community-based seniors services (including long-term care supports) to support transition to older adulthood.

This includes not only providing help to people who wish to access residential supports for seniors, but also helping people who wish to continue living with their parents or siblings to access other seniors services in the community (such as recreation or in-home supports).

The Ontario Partnership on Aging and Developmental Disabilities (OPADD) is a province-wide group of 40 agencies representing the long-term care and developmental services sectors. Their mandate is to forge new linkages between the senior services sector and the developmental services sector.

Some of the work that OPADD is doing to promote better linkages between the two sectors includes:

- Hosting 12 regional workshops across the province
- Developing 16–32 local cross-sector projects for aging people who have a developmental disability. These projects would build on the deliberations of the regional workshops
- Developing a website, publishing a quarterly Internet magazine/bulletin and providing links to relevant internet sites.

Partnering between the senior services sector and the developmental services sector has also resulted in:

- The Huron Trillium Partnership, a cooperative initiative of developmental services, long-term care and planning bodies in Huron County, investigating ways to improve co-ordination of services for seniors who have a developmental disability.
  The partnership provides a forum for addressing cross-sector planning issues and facilitates training of front-line staff and family caregivers in topics related to aging and developmental disability.
- Developmental services and long-term care providers in Peel Region are developing ways to successfully transition individuals from the developmental services sector to the long-term care sector by providing increased co-ordination of supports and services, cross-sector training and education and disability-specific consultation.

The Ministry of Community and Social Services is developing a strategy to promote cross-sector planning, service partnerships and learning by developing a protocol with the Ministry of Health and Long-Term Care. The strategy is intended to clarify expectations, roles, responsibilities and decision-making for transition planning.
The purpose of the strategy is also to provide more consistency in how the policies are applied with regard to meeting the needs of people with a dual diagnosis (i.e. people with both a developmental disability and mental health problem) and older individuals with a developmental disability who are moving to long-term care.

1.5 Supports for People with Specialized Needs

Specialized supports are needed to help people with a developmental disability and mental health issues (dual diagnosis) and/or challenging behaviour (specialized needs) and who require above-average ratios of staff support in residential and day programs, and who have greater need for specialized mental health and behavioural supports.

Agencies that provide specialized supports face challenges in recruiting individuals with the education requirements and expertise as behavioural consultants to serve this segment of the developmental services population. Effective recruitment and retention are also affected by a lack of cross-sector training and waning interest in the field of developmental services.

In May 2005, the Minister of Community and Social Services announced that the government is investing in a comprehensive strategy to enhance specialized supports for adults who have a dual diagnosis or specialized needs and to address gaps in the current system.

The components of the specialized strategy are:

- **Community Networks of Specialized Care** - Established to coordinate access to specialized resources, provide strategic direction and accountability with links to health, corrections, justice and education sectors, develop plans to recruit and train specialized professionals, and advance a research agenda. The networks will also build community capacity to prevent crises and promote early intervention strategies.

- **Recruitment and Retention** - In November 2005, the Ontario Developmental Services Career Connections Grant program was developed in partnership with the Ontario Association on Developmental Disabilities and the Northeast Mental Health Centre to promote students in specialized health professions to complete the placement component of their degree/diploma at a specialized developmental services agency.

  Universities, colleges, academic health science centres and research institutes in the networks will have responsibility to promote the recruitment and retention of specialized professionals, advance a research agenda and share their findings with other networks to identify research needs, priorities and expertise.

- **Specialized community-based accommodation** - Two complementary models of community-based accommodations will address the specific needs of people with specialized needs who have always lived in the community:

  - *Transitional accommodation* with 24-hour supervision/support for daily living activities, stabilization, assessment, specialized clinical intervention, individualized structured support, caregiver training and transition planning.
  - *Permanent accommodation* for adults with persistent high-risk behaviour who require ongoing specialized support. The objective is a safe, secure, therapeutic, long-term home.

  The specialized accommodation is intended to support people in the existing community-based system of residential supports, those living with family or those living more

independently in the community. It establishes a safety net for those who may experience a change in their needs and require more specialized, intensive supports. It provides a range of expertise that the agency system and families can turn to in urgent situations.

The objective of the transitional spaces is to build the capacity of caregivers to permanently support the individual at home or to find living arrangements more appropriate to their needs.

The permanent spaces will support adults with persistent high-risk behaviour who need ongoing specialized supports. The objective of the permanent spaces is to provide people with a safe, secure, therapeutic, long-term environment.

- **Video-conferencing** - Two video-conferencing pilot projects were created to enhance access to specialized clinical services for adults who have a developmental disability and co-existing mental health issue(s) and/or challenging behaviour living in rural and remote areas of southwestern and northwestern Ontario. The projects provide improved access to specialized professionals for individuals, their families and the caregivers and local professionals that provide support to them. This enables adults who have a developmental disability to continue to live in their homes in the community.

1.6 Taxes, Wills, Disability Savings Plans

Families caring for vulnerable family members often feel unrecognized for their contributions. Studies have shown that families caring for a family member with a disability face financial costs associated with caregiving either in the short term (e.g., reduced income and benefits due to lost time from paid employment) or in the long term (e.g., reduced retirement benefits, additional out-of-pocket expenses incurred to meet the daily needs of their child).

Tax Measures

The provincial tax system provides various indirect disability-specific supports to individuals. Some examples include the Disability Tax Credit, a non-refundable tax credit that reduces the amount of income tax owed, and the Medical Expense Credit that may be claimed for certain medical expenses including devices or supplies, and travel expenses for medical treatment that is not available locally.

Additionally, an individual who lives with, and is responsible for, the in-home care of an infirm dependent relative may be able to claim the Caregiver Tax Credit if the dependant is 18 years of age or older.

However, the tax provisions to support people with disabilities are provided primarily through the federal tax system, and many are parallel to provincial tax provisions. The Ministry of Community and Social Services will explore options relating to tax measures with the federal government.

Wills and Estates

Families are encouraged to establish trust funds and other measures for their family member who has a disability (e.g., leaving the family home in trust for a son or daughter's long-term future, designating the family member who has a disability as the beneficiary of a life insurance policy). Information about estate planning, including disability-specific tax information, is often difficult and time-consuming to find. The ministry will look at ways to make this information more readily available to families.

"As an aging parent, I'm worried about what's going to happen to [my daughter]."

- Parent

Registered Disability Savings Plans

Some families have advocated for the development of a registered savings plan for persons with disabilities similar to registered education savings plans. This type of plan would permit families who are able, to set aside some of their private savings for their family member with a disability to purchase housing and other social, educational, work and rehabilitation supports.

To help families plan and save for the future of their family member who has a disability, the Ministry of Finance and the Ministry of Community and Social Services could work with the federal government to explore the establishment of a Registered Disability Savings Plan (RDSP).

Characteristics of an RDSP might include:

- Deferred tax contributions
- Exempting interest income generated from the RDSP from taxation for the lifetime of the designated person with a disability
- Providing that RDSP income would not be clawed back by provincial or federal income programs (e.g., ODSP or Guaranteed Income Supplement)
- Allowable contributions from friends, family and extended family members.

1.7 Quality Supports and Services

As transformation proceeds, accountability and maintaining a level of quality service across the developmental services sector are important goals. Quality assurance is a form of accountability and a commitment to program integrity and evaluation and focuses on quality of service, efficiency and positive outcomes for individuals for whom the system exists.

Currently, the Ministry of Community and Social Services relies on a range of mechanisms that focus on governance and accountability in the delivery of supports to people who have a developmental disability.

Ministry-funded homes for adults with a developmental disability are not licensed by the province. However, each provider of residential services must complete a checklist of requirements focused on the personal health and safety of people living in ministry-funded group homes.

In addition, service contracts between the ministry and individual agencies are used to establish and monitor accountability and quality. Agencies are responsible for providing the ministry with regular reports addressing the organization's performance with respect to funding and financial information, program deliverables, service volumes and health and safety.

For the developmental services transformation, quality includes adhering to the principles of community participation, citizenship, safety and security, responsiveness and positive outcomes for people based on an individualized approach.

The transformation of developmental services also presents an opportunity to involve people receiving services and their families in the development of a comprehensive quality assurance system.

This work includes reviewing and improving existing quality, governance and accountability mechanisms, as well as introducing new mechanisms, to enhance provincial consistency, better reflect the evolving service system and ensure that the core values and principles driving the transformation are reflected in a system of quality assurance.

The ministry intends to develop a comprehensive system that takes a balanced approach and includes mechanisms for both assuring and improving quality and outcomes related to organizations and individuals for whom the system exists.

For example, one mechanism within a quality assurance system could be accreditation of developmental services agencies. Accreditation is a form of external audit against established standards that focuses on measurable, demonstrable outcomes and applies the same organizational standards across all services.

Many developmental services agencies have voluntarily implemented a quality assurance approach and have been accredited as a way to promote quality improvement in supports and services for people with disabilities.

"...need to imbed within the sector sustained and sufficient investments in innovation, best practice and continuous quality improvement."

- Agency

In a newly transformed developmental services sector where individuals and families have the choice of direct funding to purchase their own supports or to use existing agency programs, a flexible approach to quality assurance is needed. Quality assurance mechanisms in this area may feature criteria and outcomes that are met in a manner that is appropriate for different circumstances.

Parents have told the ministry that they are also looking for some assurance that, once they are gone, someone will speak on behalf of their adult children and protect their rights. If they have no extended family members willing or able to accept this role, they would like to know there is an independent support available.

As well, there needs to be a stronger safety net to evaluate the quality of supports and services and protect the rights of adults who are capable of living somewhat independently in the community, but who do not have parents or extended family providing them with support and supervision.

These individuals are still vulnerable and "fall between the cracks" because they are often viewed as both too skilled to benefit from traditional developmental services (e.g., day activities) and not capable of benefiting from community supports and services.

Quite often, people in these situations are also highly vulnerable to various forms of abuse. They need someone to turn to for help when their rights and safety are at risk and to speak on their behalf in gaining access to community supports and services.

The ministry funds programs (e.g., adult protective workers) through transfer payment agencies that help to protect the rights of people who have a developmental disability living in the community.

Protective service workers play a role similar to that of social workers, but provide significantly more service coordination and outreach to support independent community living, and protect and advocate for the rights of adults who have a developmental disability. Protective service workers (e.g., Adult Protective Service Worker program) play an important role in building the resilience of people who have a developmental disability. These supports can range from assistance with financial management to help with the justice system or abuse prevention.

As part of the quality assurance strategy, the ministry will build on the strengths of the existing protective service supports to provide quality assurance and protection for people living independently in the community and to be a voice for people living in residential programs offered by transfer payment agencies.

The ministry also needs to address the issue of service quality as it pertains to direct funding. The purpose of direct funding is to allow individuals/families to receive funding directly from the ministry to purchase developmental supports and services.

Quality assurance for those who choose direct funding could be in the form of a formal procedure that involves individuals or their families reporting on the use of the funding. Another option is to ask that families use their direct funding to purchase supports only from a list of approved providers.

Section 2: Plan for System Transformation

Over the past year, several strategic areas have been identified that will help achieve the objectives of fairness, accessibility and sustainability. A plan is being developed for systems transformation in the areas of:

- Independent planning
- Eligibility for developmental services and supports
- Application for funding supports
- Accessing the system of supports
- Funding approaches.

This section is intended to provide information about the ministry's plan for systems transformation. The plan is based on input received from individuals and families, agencies, family networks and provincial organizations to the Partnership Table discussion paper; at local meetings with the Parliamentary Assistant (Disabilities) and at the policy forums.

2.1 Independent Planning

Many people who have a developmental disability and their families develop their own personal plan that identifies the types of goals the person has and the areas where they need help with various aspects of their life (e.g., work, recreation, financial, education, relationships, living arrangements and medical/health services). Government funding is limited. Independent planning will help families plan for supports now and in the future and set priorities.

There also needs to be recognition that the community is able to provide things that a person needs to participate in society, and that a person who has a developmental disability or their family might need support to access these community resources.

"A facilitator would assist families to form support circles, discover community opportunities and assist with finding the best supports."

- Family organization

For people who live at home with their family, the plan might include the supports the family needs such as respite and information about supports. The personal plan also needs to focus on the community resources the person can access to address their needs, for example local employment centres, local recreation centres, volunteer literacy programs, friends, family, service clubs and community health services.

As well, there are approximately 370 developmental services agencies across Ontario providing a full range of supports. Planning can help people identify which supports are most appropriate for them.

For many people there are gaps between what they need and what community supports are available, so they turn to government-funded developmental services for help to realize some aspects of their plan.

The ministry intends to establish a network of community-based independent planners/service brokers to assist individuals and families who need and want this type of help to develop their plans, to assist in finding appropriate supports and to provide ongoing advice.

Individuals and families would not be required to use the services of an independent planner. They would have the choice to develop their own plans, to receive help with planning from an agency that provides developmental services or to use the services of an independent planner.

Independent planning teams/service brokers will play an important role in maximizing the use of all available supports, including community services available to all citizens of Ontario. The plan would be recognized as a personal statement of an individual's goals, not solely as a request for government funding, but as a blueprint of how government funding would complement the community resources a person can access. Funding would focus on how to help meet a person's needs and promote individual strengths to the extent that resources allow and within a clearly defined range of supports.

Transformation of developmental services also features a shift to providing families with the option of receiving more direct funding. This direction will be supported by a formal planning and brokerage arrangement that can help families with managing and using their funding.

Planners would also play a leading role in working with communities to promote the full participation of people with a developmental disability in the community. For example, this could include working with local business associations to promote the participation of people with a developmental disability in the workforce and encouraging local recreation services to include people with a developmental disability in their programs.

Appendix 4 provides an overview of how an individual and their family would receive supports under the transformed developmental service system.

2.2 Eligibility for Developmental Supports and Services

The first step in providing developmental services is to determine that the individual requesting supports has a developmental disability and is eligible for funded services and support. The definition of "developmental disability" is provided in the current *Developmental Services Act* and is used by service providers to determine whether a person is eligible. In the *Developmental Services Act*, the term "developmental disability" is defined as "a condition of mental impairment present or occurring in a person's formative years that is associated with limitations in adaptive behaviour." Individuals, families and service providers have asked that the eligibility criteria for supports and services funded under the *Developmental Services Act* be more clearly identified and be consistent within and across regions.

The ministry will move forward with clarifying who is eligible for ministry-funded developmental supports and services.

The ministry will convene a panel of experts in the field of developmental disabilities to assist with working out the details of these eligibility criteria, such as determining which conditions are currently acknowledged to significantly impact on an individual's development.

2.3 Application for Funding Supports

Individuals who meet the eligibility criteria for developmental disability can be considered for developmental services and/or funding. Currently, various approaches are used to determine the supports an individual can receive. These approaches are locally developed and are not standardized. Both families and service provider organizations have identified the need for equitable access to funding and supports so that people with similar needs receive comparable levels of service across the province.

"Each developmentally disabled individual has different needs and should be assessed for her/his needs to establish funding."

- Parent

The ministry is proposing the use of a standardized provincial application to determine individuals' strengths and needs for supports. The application will consist of information on key areas central to community living (e.g., social supports, employment, education) and will also be useful for determining outcomes, quality of supports, service eligibility and type of supports needed.

"Allocation mechanisms ensure that people have access, fairness and equity."

- Coalition of provincial organizations representing families and individuals with a developmental disability

Individual applications would occur at key stages in the individual's life. The concept of updating a person's circumstances according to their life stages acknowledges that there are distinct points in a person's life when there may be quite dramatic shifts in the type of support they need, and a thorough re-evaluation of the supports they are receiving is required to respond adequately to the individual's changing needs (e.g., for senior adults, the shift from work-related daytime activities to more social/recreational retirement activities).

However, a re-evaluation could occur at any time due to a change in circumstances and the need to adjust the amount of support a person needs (e.g., loss of caregiver or significant change in the individual's or caregiver's health).

The standardized application would be conducted at arm's length from the government at a community single point of access (discussed further in section 2.4) and would determine the government-funded portion of an individual's larger life plan.

Each person's strengths, preferences, needs and support requirements would be reviewed through the application, including a review of access to informal supports (e.g., non-government supports).

The application would result in an individual budget for each person. The individual budget is a notional amount for service-planning purposes and is also used to calculate the allocation of funds to various agencies.

The outcome of this approach would be improved fairness and consistency. The application process would be a standardized approach in which people with similar situations could expect to receive similar supports or funding. For example, assuming the two individuals have equal access to informal support, individuals who have higher levels of service need would have a higher individual budget for the same type of service than more independent individuals.

The application process would also provide the ministry with vital information about the developmental services system to guide policy development and aid in its work with individuals, families and agencies on service improvements and the future design of developmental supports and services.

2.4 Accessing the System of Supports

We have heard that individuals and families are looking for a more practical approach to accessing supports, one that is easy to understand and navigate. They are looking for changes to the system that provide certainty and reliability for individuals, families and service providers.

"Everything I found out about what was available was from another parent."

- Parent

In 1997, the Making Services Work for People policy initiative directed communities across the province to establish single points of access to residential services and case-resolution mechanisms for children and for people who have a developmental disability. This was intended to improve services by making the most of the residential services available in each community and to allocate resources to those most in need.

Currently, individuals who have a developmental disability and their families access ministry-funded residential services through one of 58 single points of access across the province established through the Making Services Work for People policy initiative.

Other non-residential supports for adults who have a developmental disability, such as respite, Special Services at Home (SSAH) or day supports, are obtained through the ministry's regional offices, community-based service providers and/or associations for community living – there is no single community point of access where individuals (or their families) can request the various government-funded services and supports they need.

There is considerable variation across the province in the functions undertaken by the different mechanisms established by communities, and there needs to be better consistency in how individuals are prioritized to receive service and with respect to common intake tools and the collection and sharing of information.

A more formal planning and facilitation process is needed so individuals and families can learn about available supports, how to access supports and, for families, how to plan for the future care and support of their family member who has a developmental disability. Individuals and families need single points of access to build a service and support plan to meet the individual's needs appropriately, rather than managing supports and fitting people into what is available.

"Government should ensure there is one place to call for all community services, with available information on all sectors."

- Agency

The single point of access could serve the following functions:

- **Inquiry** – handling an initial contact or responding to general questions about the service system
- **System navigation** – helping individuals and families to understand and find supports
- **Information/referral** – providing information and referrals to specific supports and programs
- **Eligibility determination** – determining whether an individual/family is eligible for a specific service/program
- **Application for service** – evaluating an individual's application to better understand the person's strengths and needs
- **Authorizing/allocating resources** – evaluating level of need and allocating appropriate resources
- **Resource and advice**– acting as a resource to individuals and families to provide advice and guidance on the coordination of services and supports including transition planning
- **Outcomes reporting** – collecting, managing and reporting data.

This approach is intended to create a single point of access in communities where individuals or their families can request the various services and supports they need. This approach will create consistency by standardizing the functions undertaken by the different mechanisms established by communities and how individuals are prioritized for supports.

It will also create consistency with respect to common intake tools and the collection and sharing of information so people don't have to tell their story over and over to multiple agencies.

2.5 Funding Approaches

There are approximately 370 non-profit agencies delivering community-based services in Ontario. They offer a wide range of developmental services to thousands of people and respond to a very wide range of individual needs.

Among the services offered by agencies are:

- Residential supports such as group living, familyhome arrangements and supported independent living
- Respite (in-home and out-of-home)
- Community supports such as day programs, Passport (including the former Foundations programs), employment and vocational alternative supports and
- Specialized community supports including assessment and counselling services and speech and behaviour management/ intervention.

A great number of individuals and their families are pleased with the services offered by agencies and would like to continue to receive services from them. Some families receiving services from agencies would like to continue with this arrangement, but would like a greater say in how those services could be offered to better meet the strengths and needs of their family member. Many agencies would welcome this opportunity to work more creatively with individuals who have a developmental disability and their families on innovative approaches to providing services and would like the ministry to create ways for them to provide supports differently to respond to families' needs.

Transformation of developmental services depends on maintaining a healthy agency sector. The agency system is vital to ensuring that the community capacity exists to support community living for people who have a developmental disability. The ministry will work with the sector to develop human resource strategies that will include addressing issues related to pre- and in-service training.

Other individuals and families have told the ministry that the developmental services system should offer them increased choice and flexibility and stimulate innovation and creativity. These families have asked for direct funding as an alternative to receiving support through an agency. Direct funding is the allocation of financial resources to individuals by government to allow them to purchase the supports and services they need. It provides individuals who have a developmental disability and their families with considerable choice and flexibility over how supports are provided and by whom.

The ministry recognizes that the current system does not meet everyone's needs. While overall funding will be based on available resources, a funding model will be introduced that gives individuals and families the choice to receive direct funding and gives them the flexibility to purchase their supports.

As the transformation matures, the funding model will evolve into a system with the following elements:

- Once an individual's funding for developmental services has been determined, they and/or their family would choose to receive agency-funded services or direct funding.

- Supports could include a combination of individualized supports, such as in- and out-of-home respite, day supports, residential, social/recreational or vocational alternative supports.

- Individuals and families may continue to receive some or all of their services from an agency. If they choose to receive support from an agency, the funding that is specified in an individual's budget would flow to the agency providing the services. The agency would have responsibility for providing services to each individual as specified in the individualized support plan.

- Some families may opt to receive funding directly and purchase supports on their own. Some might need assistance to secure, coordinate and monitor supports and to assist with realizing the goals of the support plan that was developed with the help of their independent planner.

- One option would be to receive the assistance of a broker to manage the funds and purchase supports according to the individual's support plan (or their assessed disability-related needs). The decision about the most appropriate service providers could be made with the help of the individual's independent planner, or people may opt to use the service coordination and brokerage function offered by the single point of access.

The transformed funding model will result in a fair approach by basing each individual's budget on a common application form that highlights their strengths, functional abilities, needs and support requirements and by taking into account their access to informal supports. The funding model will also be fair for agencies because their funding will be determined on the basis of current needs of the people they serve and current unit costs.

A fair approach in the transformed funding model will also promote sustainability of the developmental services system.

Conclusion

Tremendous commitment is needed from individuals, families, agencies, communities and government in undertaking this transformation of supports and services for people who have a developmental disability. The principles and strategies put forward are ambitious and have implications for all aspects of society including individuals who have a developmental disability, their families, agencies who deliver services for people who have a developmental disability, all levels of government, schools, business, the volunteer sector and other members of the community at large.

Delivering on the transformation involves new ways of working in more effective partnerships. Together, it will support Ontario's vision of full inclusion of people who have a developmental disability in all aspects of society and achieve the objectives of:

- Independence, dignity and self-reliance for people who have a developmental disability
- Strong families supported to care for their family members who have a disability with the help of strong communities
- A fair and accessible system and
- A sustainable community-based service system.

"To encourage all the players to work together to carry out their roles and responsibilities, there must be value seen in the individual. This value needs to be promoted. Supporting vulnerable people is a privilege not a burden of being a member of society."

- Organization representing front-line workers

Appendix 1: Guide to Consultation Questions

The following consultation questions provide an opportunity for all Ontarians to express their views about the proposed changes to supports for people with a developmental disability. We want to hear from you. The following questions correspond to the topics found in section 1 of the paper. You may wish to answer the questions that are provided or write additional comments or ideas.

Anyone who has an interest in how funding and supports are provided to people who have a developmental disability is encouraged to participate in this process, either as an individual or as part of a group or organization.

To provide your feedback electronically: visit our website at www.mcss.gov.on.ca and click on "Transforming Developmental Services".

1.1 Support for Inclusion and Community Engagement

Individuals, families, agencies and government need to work together to strengthen the voice of people who have a developmental disability – and make it easier for them to participate fully as citizens in their communities.

Key Questions

1a. What makes it hard for a person with a developmental disability to be active and included in the community?

1b. What would make it easier to be active and included? Who can make these changes happen and how might they go about it?

Optional Detailed Questions

1c. What do you see as the role of the various players in making it easier for people to be included in their community? Think about:

- Individuals who have a developmental disability
- Their families
- Agencies who support people who have a developmental disability
- Other community organizations (voluntary organizations, schools, business, faith/culture organizations)
- Governments (federal, provincial, municipal)

1d. Do you know of any examples of successful partnerships among some or all of these players that others could learn from? Please describe what is happening and what makes it work.

1e. Are there particular cultural considerations that you know about that will need to be addressed appropriately in plans for including people fully in the community?

1.2 Respite for Caregivers

There are good supports available now (called "respite" supports) to give families brief breaks from caring for an individual who has a developmental disability. But the system is very complicated and could be made simpler and more effective.

Key Questions

2a. What types of relief ("respite") from caregiving responsibilities are most needed by families?

2b. What would you like to see in the "best possible" system of family relief? What would be offered? How would it work?

Optional Detailed Questions

2c. What currently prevents families from getting the relief they need? How would you suggest that these challenges be overcome?

2d. Are there special needs – emergency situations, for example – that require something different from the standard respite approach? What is different and how can these needs be met?

1.3 Partnerships with Families on Residential Supports

We need to explore how ministries and families can best collaborate to support individuals' living arrangements outside the family home. For example, some families may wish to use their own resources to provide a home for a family member outside the family home. We also need to work to remove some of the barriers that currently exist. There may be other, innovative options – perhaps involving partnerships among governments and voluntary organizations.

Key Questions

3a. What can the ministry do to better support individual choice of how and where to live – within or outside of existing ministry-supported arrangements?

3b. Do you know of any examples of successful partnerships among families, agencies, community groups and government in creating new kinds of living arrangements?
Please describe what is happening and what makes it work.

Optional Detailed Questions

3c. What barriers must be removed or incentives provided to individuals, families or agencies to encourage the creation of innovative residential options? (Think about funding, legislation, social assistance or other programs)

3d. What supports need to be in place to help protect the safety and security of vulnerable people living on their own?

3e. What improvements could be made to existing choices?
- Group homes?
- Supported independent living?
- The Familyhome program?

1.4 Transition across Life Stages

Examples of life transitions are when a young person leaves school or when an adult becomes a senior citizen. Making the adjustment to different support needs and different sources of support can be difficult. We need to find better ways to help individuals and families plan for these transitions in advance, and make them successfully.

Key Questions

4a. What information and support would be of most help to individuals and families as they plan for the transition from school to adult supports?

4b. What programs and supports need to be in place for seniors who have a developmental disability?

Optional Detailed Questions

4c. Who should be involved in planning transitions from school to adult support?

4d. What existing services for seniors are available to people with a developmental disability (whether they live with family, on their own or in government-funded residential supports)?

4e. Do you know of any examples of successful partnerships among individuals, families, schools, community organizations and governments to support life transitions that others could learn from? Please describe what is happening and what makes it work.

1.5 Supports for People with Specialized Needs

Special supports, beyond those available through community mental health and counselling services, are needed when people who have a developmental disability face mental health and/or behaviour issues. The ministry has recently put special supports in place for these individuals (called specialized services), but there are still gaps between what is needed and what is provided.

Key Questions

5a. What are the gaps between what is required by people with specialized needs and what is provided?

5b. What suggestions do you have as to how best to close these gaps?

Optional Detailed Question

5c. How can the specialized services recently introduced by the ministry best work together with the core service system?

1.6 Taxes, Wills, Disability Savings Plan

While all parents have a legal responsibility to support their children until they turn 18, many parents who have a family member with a developmental disability continue to provide financial support throughout their adult years. Instead of contributing towards university tuition costs, as they might for a son or daughter who does not have a disability, one parent may stay out of the workforce to provide support at home and to provide transportation to work or volunteer activities in the community. There is an opportunity to get the provincial and federal tax systems working together more effectively to help address the additional financial costs faced by caregivers. This includes exploring the possibility of creating a registered savings plan for people with disabilities (similar to registered education savings plans). Families are also looking for changes in how they can use wills and trust funds to support a family member.

Key Questions

6a. What changes are needed to help families cope financially as they care at home for their family member with a disability?

6b. What changes would help families who want to make long-term plans to support their family members with a disability?

Optional Detailed Question

6c. What are the best ways to get people the information they need about wills, trusts and other plans to support their family member with a disability?

1.7 Quality Supports and Services

There is an opportunity to involve people receiving supports and services and their families in setting acceptable quality standards, and developing ways to improve the quality of services and supports provided to them.

Key Questions

7a. What role should individuals and their families play in setting quality standards for supports delivered by agencies, and for supports purchased elsewhere?

7b. How can individuals and their families contribute to the continual improvement of the quality of services and supports provided?

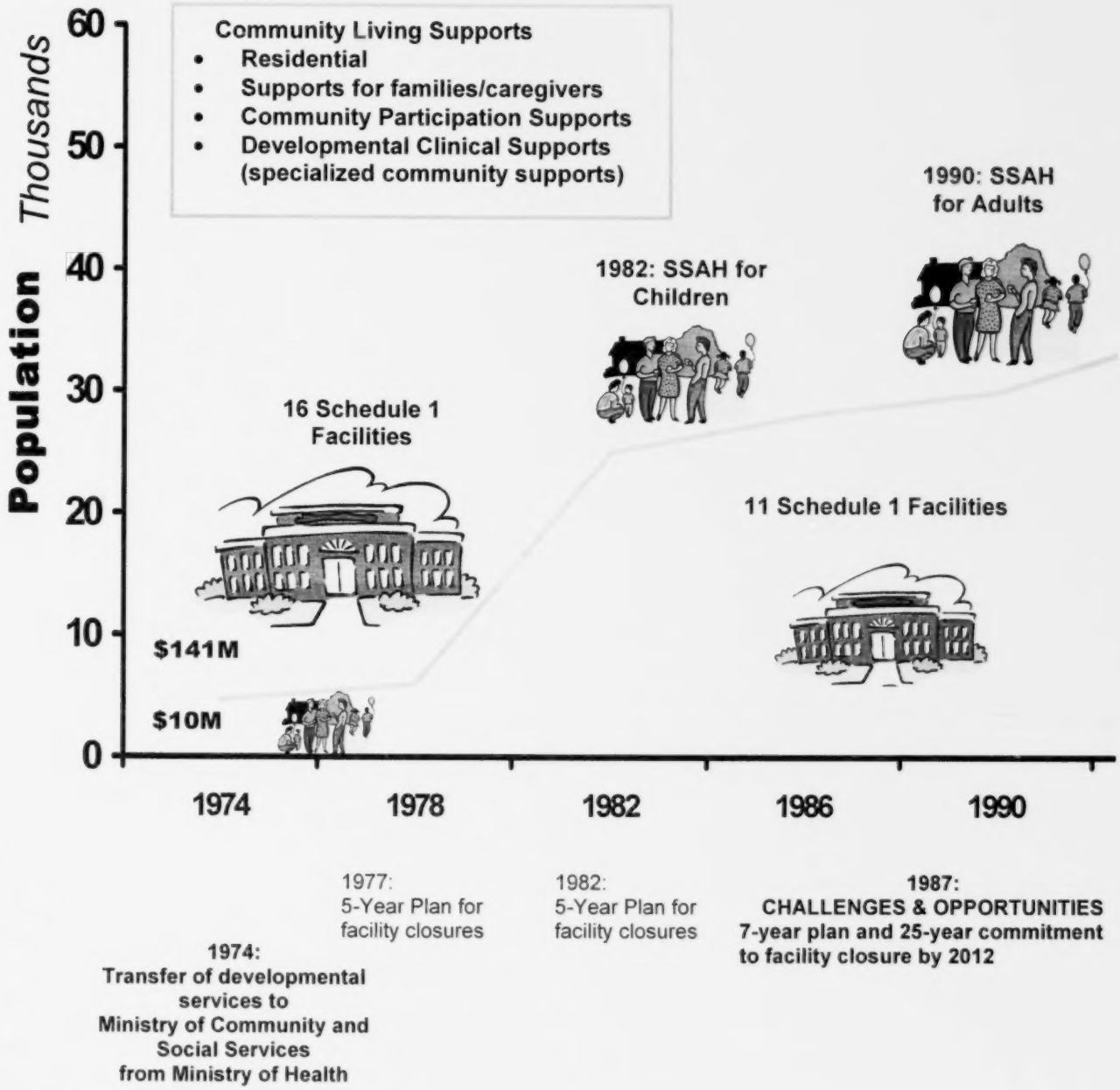
Optional Detailed Question

7c. What needs to be put in place to monitor the quality of supports and services provided to individuals and their families (through agencies, or purchased directly from elsewhere) against agreed standards?

What Else Would You Like to Say?

Is there anything else you would like to say about the services and supports provided to individuals with a developmental disability and their families that you have not already said?

Appendix 2: Milestones in the Expansion of Community Living



2001:
MULTI-YEAR PLAN
1. Agency Revitalization
2. Places to Live
3. Community Supports

2004:
Developmental Services Transformation

1997: ODSP & Making Services Work for People

$1B

6 Schedule 1 Facilities

3 Schedule 1 Facilities

$107M

1994 **1998** **2002** **2003**

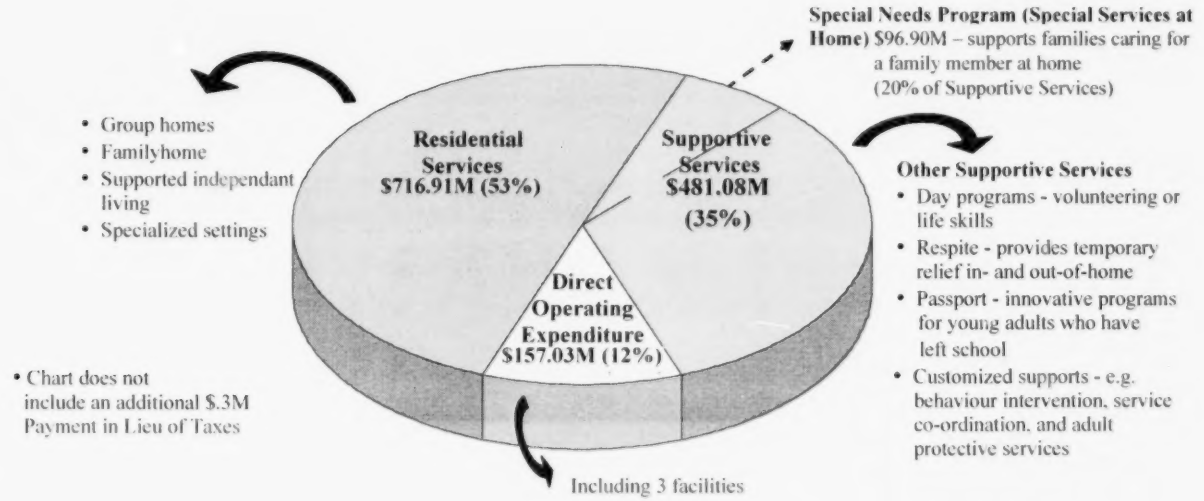
1996: COMMUNITY LIVING INITIATIVE
4-year plan for facility closures

2004: FACILITIES INITIATIVE
5-year plan to close remaining facilities by March 31, 2009

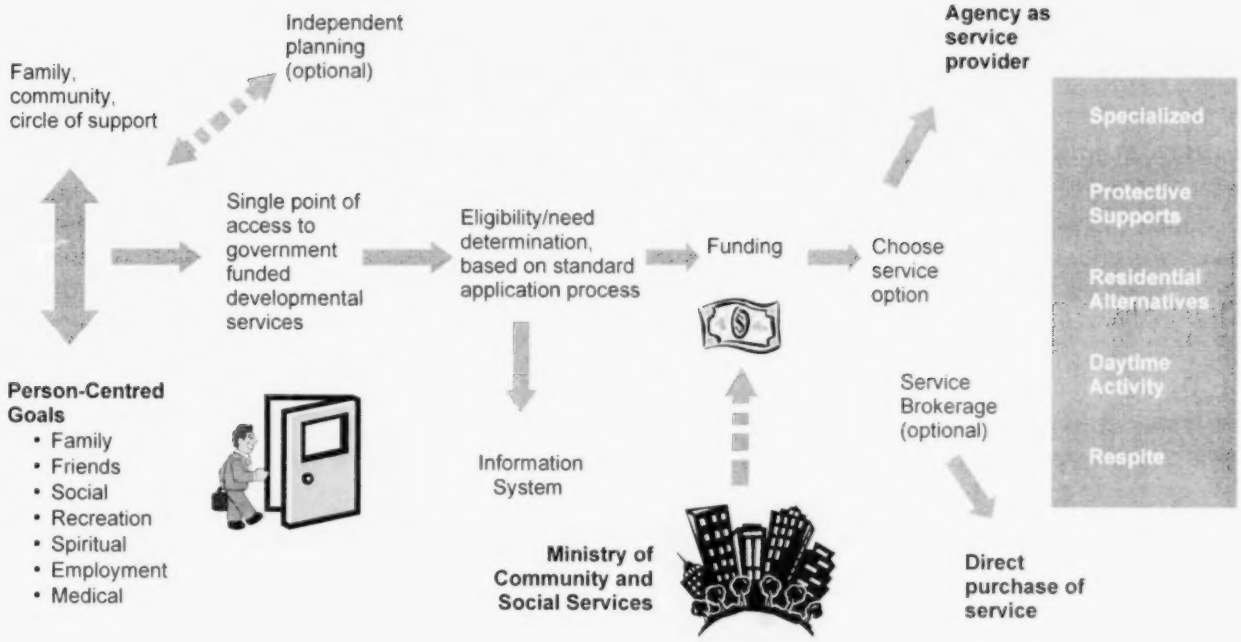
Appendix 3: Program Expenditures in Developmental Services

- Approximately 41,000 adults who have a developmental disability receive income support through the Ontario Disability Support Program (ODSP)
- Almost 370 non-profit agencies deliver developmental services and employ more than 18,000 staff
- Three facilities for adults who have a developmental disability (scheduled to close by March 31, 2009)

Developmental Services 2006/07 Printed Estimates - $1,355.32M


Special Needs Program (Special Services at Home) $96.90M – supports families caring for a family member at home (20% of Supportive Services)
• Group homes
• Familyhome
• Supported independant living
• Specialized settings
Residential Services $716.91M (53%)
Supportive Services $481.08M (35%)
Direct Operating Expenditure $157.03M (12%)
Other Supportive Services
• Day programs - volunteering or life skills
• Respite - provides temporary relief in- and out-of-home
• Passport - innovative programs for young adults who have left school
• Customized supports - e.g. behaviour intervention, service co-ordination, and adult protective services
• Chart does not include an additional $.3M Payment in Lieu of Taxes
Including 3 facilities

Appendix 4: New Funding System for Developmental Services



© Queen's Printer for Ontario, 2006
ISBN 1-4249-0921-X (Print)
ISBN 1-4249-0923-6 (PDF)
ISBN 1-4249-0922-8 (HTML)
Ce document est également disponible en français.